

ความสัมพันธ์ระหว่างคุณภาพชีวิตครอบครัวและการะของผู้ดูแลเด็ก ที่มีภาวะออทิสซึมในครอบครัวในประเทศเวียดนาม Relationships between Family Quality of Life and Burden among Family Caregivers of Children with Autism in Vietnam

นิพนธ์ต้นฉบับ

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Original Article

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บทคัดย่อ

วัตถุประสงค์: เพื่อศึกษาคุณภาพชีวิตครอบครัวและการะของผู้ดูแลเด็กที่มีภาวะออทิสซึมในครอบครัว และศึกษาความสัมพันธ์ระหว่างคุณภาพชีวิตครอบครัวและการะ **วิธีการศึกษา:** การศึกษาเชิงพรรณนาและหาความสัมพันธ์ ดำเนินการที่แผนกผู้ป่วยนอก (OPD) ของโรงพยาบาลกุมารเวชศาสตร์แห่งชาติ ซึ่งตั้งอยู่ในกรุงเทพมหานคร ประเทศเวียดนาม สุ่มตัวอย่างแบบสะดวกในการคัดเลือกครอบครัวผู้ดูแลเด็กออทิสติกจำนวน 50 คน เครื่องมือที่ใช้ในการวิจัย ได้แก่ แบบสอบถามข้อมูลประชากร แบบวัดคุณภาพชีวิตครอบครัวของ Beach Center และดัชนีความเครียดผู้ดูแล วิเคราะห์ข้อมูลด้วยสถิติเชิงพรรณนาและค่าสัมประสิทธิ์สหสัมพันธ์ของเพียร์สัน **ผลการศึกษา:** ผู้ดูแลในครอบครัวรับรู้คุณภาพชีวิตครอบครัวโดยรวมในระดับต่ำ ($M = 1.52, S.D. = 0.22$) และการะในระดับสูง ($M = 3.81, S.D. = 0.32$) พบมีความสัมพันธ์เชิงลบอย่างมีนัยสำคัญระหว่างคะแนนรวมคุณภาพชีวิตครอบครัวและการะผู้ดูแล ดังนั้นจึงคุณภาพชีวิตครอบครัวต่ำลงการะผู้ดูแลก็ยิ่งสูงขึ้น นอกจากนี้ พบความสัมพันธ์เชิงลบระหว่างการมีปฏิสัมพันธ์ในครอบครัว การเลี้ยงดู ความเป็นอยู่ที่ดีทางอารมณ์ กับการะของผู้ดูแล **สรุป:** การค้นพบนี้ชี้ให้เห็นว่าพยาบาลและผู้ให้บริการด้านสุขภาพที่ดูแลครอบครัวและเด็กที่มีภาวะออทิสซึม ควรให้ความสำคัญกับการจัดตั้งทีมดูแลสหสาขาวิชา รวมทั้งให้การสนับสนุนครอบครัวมากขึ้นเพื่อเพิ่มคุณภาพชีวิตครอบครัวและจะช่วยลดการะผู้ดูแลครอบครัว ซึ่งส่งผลดีทางบวกสำหรับเด็กที่มีภาวะออทิสซึม

คำสำคัญ: ภาวะออทิสซึม, คุณภาพชีวิตครอบครัว, การะ, ความสัมพันธ์ ประเทศเวียดนาม

Abstract

Objective: To examine family quality of life and burden of family caregivers of children with autism, and determine relationships between the family quality of life and burden. **Methods:** A descriptive correlational study was conducted at the Outpatient Department (OPD) of the National Hospital of Pediatrics located in Hanoi, Vietnam. A convenience sampling method was used to recruit 50 family caregivers of children with autism. Research instruments included a demographic questionnaire, the Beach Center Family Quality of Life Scale and the Modified Caregiver Strain Index. Descriptive statistics and Pearson correlation coefficients were used for data analysis. **Results:** The family caregivers perceived a low level of the overall family quality of life ($M = 1.52, S.D. = 0.22$), and a high burden level ($M = 3.81, S.D. = 0.32$). There is a significant negative correlation between the total score of family quality of life and caregiver burden, therefore, the lower the family quality of life, the higher caregiver burden. Furthermore, there were negative relationships between their subscales of family interaction, parenting, emotional wellbeing and caregiver burden. **Conclusion:** Nurses and health care providers responsible for family and children with autism should pay more attention to establish a multi-disciplinary care team and provide more family support to increase family quality of life and thereby reduce family caregiver burden. Consequently, positive outcomes for children with autism would also be achieved.

Keywords: autism, family quality of life, burden, relationship, Vietnam

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Introduction

According to the Centers for Disease Control (CDC), the rate of autistic children is increasing rapidly and the prevalence rates of autism in the United States are estimated at approximately one in 88 children.^{1,2} In Vietnam, this rate raised up 50 times over the period of 2000 to 2007 at the National Hospital of Pediatrics and increased to 160 times in Ho Chi Minh City.³ On average, children identified with autism were diagnosed after the age of 4 years old even though they could be diagnosed as early as age 2. Even so, clinicians prefer not to diagnose them at age two, but rather wait until

age four to prevent labeling or stigma. Autism diagnosis and treatment methods remain controversial and are mostly based on behavioral history and assessments. Moreover, there are many parents who known their child with behavior problems. However, they tried to hide the problems or provide incomplete information, making it difficult to diagnose and treat children with autism.⁴

Families of children with autism play a critical role in their child's ability to adapt and live in daily life as well as receiving treatments. Externalizing behaviors of children with autism

seem to be persistent and stable over time and create substantial problems for the children, their families, and people around them.⁵ Autistic children have difficulties or deficits in communication and socialization skills.⁶ Children with autism usually lack skills in self-care, communication and socialization. As a result, caregivers spend a lot of time and effort taking care of and helping children adjust to their daily life. Families with traditional belief may easily assume that it is the punishment for their bad behaviors in the past life. This stigma creates difficulties in finding information and service systems related to a child's disability, leading to higher family stress and depression, and low quality of life. Therefore, family members, especially parents, have to spend numerous time to help the children adapt with their daily life. The costs for raising a child with autism is more than three times compared to the costs of raising a non-affected child because of necessary expenses related to special education, health and social services.⁷ Additionally, information and service systems are difficult to understand and approach by families with new diagnosis.⁸ In some countries with traditional belief, parents often hide their child's disabilities and developmental delay to receive treatment. By taking of various roles and challenges, families of autistic children report low family quality of life and a high burden.^{9,10}

Family quality of life (FQOL) is how family members identify and inform the dynamic sense of well-being of the family as a unit, collectively and subjectively.¹¹ It is conceptualized as a multidimensional construct, including, family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support. Evidence showed that low FQOL resulted in several problems among family members for both psychological and physical health and well-being.^{12,13} A research related to FQOL of families with autistic children revealed that low FQOL can potentially result in negative family's capabilities and skills to deal with adversities and challenges across their entire lifespan.¹⁴ Therefore, low FQOL in turn, affect to autistic children outcomes as well.

Family caregiver's burden refers to perception of a family caregiver about difficulties, strains, and other negative effects as a result of caring for a child with autism when the demands of care-giving outweigh the available resources.¹⁵ Raising a child with autism brings big challenges for caregivers.^{16,17} Meeting the high care needs of children with autism requires numerous time, effort and patience for family caregivers. Due

to the severity and chronic characteristics, the children with autism accompany physical conditions, combined with poor self-care and adaptability, they have a high need for medical services as well as special education in implementing general and special interventions.¹⁸ In addition, parents most frequently have to quit their job or cut hours to stay at home for caring of their children or bring them for follow-up treatment at a clinic.¹⁹ For these reasons, parents as family caregivers could face high burden while rearing children with autism. Therefore, taking care of a child with autism increases the family caregiver's burden by forcing caregivers to adjust their daily lives to the child's special educational and medical needs.

From literature review, researchers mentioned that families of children with autism experienced significant level of burden that affects their FQOL.^{12,15,20} Findings from a study reported that there is a positive correlation between FQOL and the subjective burden and associated with the care of children diagnosed with autism.¹² A mixed methods study related to caregivers of children with autism found that burden is a statistically significant predictor of FQOL in the negative direction. Moreover, the results of qualitative research indicated that caregiver burden affects FQOL.¹⁵ There are many studies on the burden and FQOL of families of children with autism. However, those evidences reported overall FQOL results. Yet, it is significant to examine how the burden related to each component of FQOL, namely, family interaction, parenting, emotional well-being, physical/material well-being, and disability-related support. This study could provide information about family caregiver burden and FQOL as a whole and its components, especially in Vietnamese family caregivers caring for children with autism. Moreover, the relationships between caregiver burden and FQOL identified would be beneficial for further studies to plan or implement a program to help lessen caregiver burden and improve FQOL. We hypothesized that there were relationships between caregiver burden and a FQOL of Vietnamese family caregivers of children with autism.

Methods

This descriptive correlational study employed a convenience sampling technique to recruit the participants through the target population. Of the 283 caregivers assessed for eligibility, who accompanied autistic children for the health

services at a national children's hospital in Hanoi, Vietnam in 2019, there were 50 family caregivers volunteered to participate. This sample was a part of a pre-implementation phase of a randomized controlled trial study. To be eligible for participant recruitment, caregivers had to be the primary caregiver of a child with autism from three to eight years old, have a biological relationship with the child, provide care to a child without receiving a wage or payment, live in the same house with the child at least six months prior to data collection, have the ability to read and understand Vietnamese language, and be willing to participate in the study. The caregivers who had a serious physical or mental health problem were excluded from the study. As recommended by Bonett and Wright²¹, a minimum sample of 50 is adequate to perform Pearson correlation.

Ethical considerations

This study was granted approval from the Institutional Review Board (IRB) from a university (Code number 02-04-2562) and permission for collecting data from the Vietnam National Children's Hospital, Research Institute for Child Health Ethic Committee (Reference number VNCH-RICH-2019-61).

Research instruments

A **demographic questionnaire** was developed by the principal investigator (PI). The PI interviewed the participants and completed it. It contained two sections of information about the caregiver's and the children's characteristics. For the caregivers, there were age, relationships with children, gender, marital status, educational level and occupation. For the children, there included age, number of siblings, duration since diagnosed, gender and birth order.

The **Beach Center Family quality of life Scale** developed by Hoffman and colleagues²² was used to measure FQOL of the participants. The scale included 25 self-report items with five domains of: a) family interaction (6 items), b) parenting (6 items), c) emotional well-being (4 items), d) physical/material well-being (5 items), and e) disability-related support (4 items). The participants were asked to answer on how much they perceived their FQOL by rating on a 5-point rating scale from 1 (very dissatisfied) to 5 (very satisfied). It usually took about 10 - 15 minutes to complete this questionnaire. The total score ranged from 25 to 125, which were summed from all items' score. The scores of each subscale were 6 - 30 for family

interaction, 6 - 30 for parenting, 4 - 20 for emotional well-being, 5 - 25 for physical/material well-being, and 4 - 20 for disability-related support. The higher total and subscale scores indicated the better FQOL and each subscale, and the lower total and subscale scores indicated lower FQOL and each subscale. However, for the purpose of interpretation as levels of FQOL both a total and subscales, a possible range score of mean 1 - 5 was then equally categorized into 3 levels of low (1.00 - 2.33), moderate (2.34 - 3.33), and high (3.34 - 5.00).²³ In this study, Cronbach's alpha coefficient of the Beach Center Family quality of life scale was 0.78.

The **Caregiver's Strain Questionnaire** developed by Brannan, Bickman and Heflinger²⁴ was used to measure burden of the family caregiver about the degree to which family experience difficulties, strains, and other negative effects as a result of caring for a child with autism. The scale included 21 self-reported items with two subscales of objective (11 items), and subjective (10 items) burden. The participants were asked to answer and rate on how much their families perceived burden for the care. Each item contained a 5-point rating from 1 (not at all) to 5 (very much). Scores were summed and divided by 21 to provide a mean of total score, and mean subscales' score divided by a total number of items in each subscale. For the purpose of interpretation as levels of burden, a possible range score of mean 1 - 5 was then equally categorized into 3 levels of low (1.00 - 2.33), moderate (2.34 - 3.33), and high (3.34 - 5.00).²³ The high score indicated more burden of care, and the low score indicated less burden. In this study, Cronbach's alpha coefficient was 0.82.

The Beach Center Family quality of life Scale and The Caregiver's Strain Questionnaire were original in the English language. Therefore, they were translated into Vietnamese language by using the WHO (2016) guidelines.²⁵

Data analysis

Data were analyzed by using a statistical software computer program. Descriptive statistics were used to describe characteristics of the participants and the children, and the study variables of FQOL and caregiver burden. Statistical significance level was set at P -value < 0.05. Pearson correlation coefficients were used to examine relationships between FQOL and burden of Vietnamese family caregivers of children with autism.

Results

A total of participants was 50 family caregivers (Table 1). Their average age was 36.1 years ($SD = 8.39$), and average years of duration of care was 5.58 years ($S.D. = 1.91$). Most of them were parents of autistic children (96.0%), female (80.0%), married (68.0%), and worked as government officers (56.0%). The children with autism had average age of 5.8 years ($SD = 1.63$) with a range of 4 - 9 years. The average year of being diagnosed with autism by a physician was 2.56 ($S.D. = 1.46$). Most of them were boys (86.0%), the first child in the family (76.0%), and had 1 - 2 siblings (Table 1).

Descriptive statistics of the study variables and their subscales

The total mean score of the FQOL was 1.52 ($S.D. = 0.22$), indicating that the caregivers of children with autism had a low level of FQOL (Table 2). Considering all five subscales of FQOL, family interaction, parenting, emotional well-being, physical/material well-being, and disability related support, they were at a low level. The total mean score of the caregiver burden was 3.81 ($S.D. = 0.32$). It indicated the caregivers of children with autism had a high level of burden. For its subscale, subjective and objective burdens, they were also at a high level.

Relationships between FQOL and burden among Vietnam family caregivers of children with autism

Since all assumptions for Pearson correlation analysis were met, the analysis was appropriate. The results showed that FQOL's total score was negatively correlated to burden among family caregivers of children with autism ($r = -0.43$, P -value < 0.01), indicating that the participants who had higher FQOL would have lower burden; on the other hand, the participants who had lower FQOL would have higher burden (Table 3). Three subscales, including, family interaction, parenting and emotional well-being were negatively correlated to burden ($r = -0.30$, $r = -0.32$, and $r = -0.32$, P -value < 0.05 for all, respectively). These also suggested that the participants who had higher family interaction, parenting, and emotional well-being would have lower burden, on the other hand, the participants who had lower family interaction, parenting, and emotional well-being would have higher burden. However, the two subscales of physical/material well-

being and disability-related support were not significantly correlated (P -value > 0.05).

Table 1 Demographic characteristics of caregivers and children with autism (N = 50).

Characteristic	n	%	M	S.D.	Range
Child					
Age (Year)			5.78	1.63	4-9
Number of siblings			1.01	0.20	1-2
Duration since diagnosed (yrs)			2.56	1.46	1-5
Gender					
Boy	43	86			
Girl	7	14			
Birth order					
1 st	38	76			
2 nd	12	24			
Caregiver					
Age (years)			36.08	8.39	24-72
Duration of care (years)			5.58	1.91	1-9
Relationship with the children					
Parents	48	96			
Grandparents	2	4			
Gender					
Female	40	80			
Male	10	20			
Marital status					
Married	34	68			
Single	3	6			
Divorced	13	26			
Education					
Primary school or lower	8	16			
Secondary school	7	14			
High school	3	6			
Diploma/ college	13	26			
University or above	19	38			
Occupation					
Officers	28	56			
Farmers	13	26			
Industrial workers	8	16			
House wife	1	2			

Table 2 Family quality of life and caregiver burden for total and subscale scores (N = 50).

Variable	M	S.D.	Level
Family quality of life			
Total	1.52	0.22	Low
Subscale			
Family Interaction	1.53	0.23	Low
Parenting	1.67	0.37	Low
Emotional well-being	1.40	0.44	Low
Physical/Material well-being	1.68	0.30	Low
Disability-related support	1.52	0.29	Low
Burden			
Total	3.81	0.32	High
Subscale			
Objective	3.77	0.26	High
Subjective	3.82	0.25	High

Table 3 Pearson's correlation coefficients between family quality of life, both total and subscale scores, and caregiver burden (N = 50).

Variable		Burden (<i>r</i>)
Family quality of life	Total	- 0.43**
	Subscale	
	Family interaction	- 0.30*
	Parenting	- 0.32*
	Emotional well-being	- 0.32*
	Physical/Material well-	- 0.17
	Disability-related support	- 0.15

** *P*-value < 0.01; * *P*-value < 0.05.

Discussions and Conclusion

This study aimed to examine FQOL and burden among Vietnamese family caregivers in giving care for children with autism and determine relationships between FQOL and burden. The study results revealed that the caregivers perceived a low level of the overall FQOL and its subscales. Considering each subscale, the highest mean score was physical/material well-being, followed by parenting, and the lowest was emotional well-being. The results of this study are in contrast to a research on families of children with autism in developed countries that the majority of families rated the family quality of life as moderate, good, or even excellent.^{9,26} The possible reason for these differences is that in developed countries the availability of facilities and social welfare could make family caregivers have a higher FQOL. In addition, the development of medical and special education services made families to easily access and update information about these services, facilitating early diagnosis and effective intervention on children as well as their own family problems. However, this study findings were similar to studies on the family quality of life in family of children with autism in developing countries that they have poor FQOL. A study in China found that FQoL was at medium and low levels.²⁷ Another study in Israel on family of children with disabilities indicated that families generally had low and moderate scores on FQOL.²⁸ This may explain that although awareness of autism in some Asian and middle-income countries, especially Vietnam, is widespread, it has yet to develop. As a result, families of children with autism in this study still face significant challenges in accessing diagnostic, intervention and educational services.²⁹ Medical and special education services for children with autism are

scarce, often overwhelmed or unreliable. Families must take care of and support their children themselves, and bear the cost of any necessary professional services without receiving any physical or emotional support.

Among subscales' scores, research evidence addressed that the evaluation of FQOL subscales' scores provided more understanding than overall score. The study results indicated that family views better physical/material well-being and poorer emotional well-being. This finding was supported by other studies.^{30,31} Most likely, the age of Vietnamese family caregivers was still young and healthy ($M = 36.1 \text{ years} \pm 8.39$). Moreover, the majority of caregivers lived with their spouses, therefore, they had financial sharing as well as child care. Therefore, the families perceived a higher physical/material well-being and parenting compared to other domains. However, the lowest emotional well-being can be explained by the fact that most of children with autism were the first child in their family. Moreover, Vietnam is a developing country in Southeast Asia influenced by traditional beliefs; therefore, the stigma of a Vietnamese family with an autism has increased the caregiver's emotional problems because of abnormal behaviors of their children, and the community's lack of understanding of the nature of the children with autism.³ In addition, the health information and service system could not be effectively accessed by families.^{32,33} These problems make caregivers in Vietnam had a low level of emotional well-being.

Family caregivers of children with autism in the current study demonstrated high level of burden ($M = 3.81 \pm 0.32$). Living with an autism, the family caregivers had to spend numerous times to take care and help the children in adapting with their daily life; keeping their eyes on the lifelong children; absent from their works or restricted career due to their responsibilities for the children; changing their work situation; and cutting hours or giving up work entirely and losing benefits.^{34,35} This result was congruent with previous research, which indicated that caring for a child with autism is associated with increased family caregiver burden across the child's lifespan.³⁴

The study result revealed that family caregivers had a high level of subjective burden ($M = 3.82$, $S.D. = 0.26$). A previous research examined the impact of autism on emotions experienced by caregivers. The authors indicated that caregivers tend to respond with grief and anger, doubt and guilt, disappointment and sacrifice, and experience relationship strain.³⁶ Possible influence on this result may

stem from cultural background of Vietnam as more serious and traditional. Family usually thought that this is punishment for their guilt in the past life. Therefore, they often hide their child who has disabilities or developmental delay, and not taken the child to receive medical and special educational services, and resulting in high stress, depression and burden on the family caregivers.^{10,37} Additionally, other explanation for the high level of burden of the family caregivers is that, nowadays, autism is a common problem. Yet, information and service systems are rarely and difficult to understand and approach in Vietnam.^{3,38} Moreover, Vietnamese children with autism could only receive proper medical treatment and behavior intervention services in tertiary or university hospitals.

The study results indicated that there is a significant negative correlation between the total score of FQOL and caregiver burden. Therefore, the participants with higher FQOL would have lower burden, on the other hand, the participants with lower FQOL would have higher burden. It is understood that those who give care for children with autism play various roles in the child's life; therefore, they had low FQOL and made them bear a considerable level of burden. Because of behavioral problems, children with autism have poor adaptability to everyday life, so caregivers act as primary caregivers to help children adapt to everyday life. Children with autism having problems with mental and physical conditions, caregivers act as medical staff to devise intervention programs as directed by a doctor and psychiatrist. In addition, children with autism have special education needs, then, the caregivers act as child's special educators changing behavioral problems. Through these roles, it is possible to explain that the FQOL was related to family caregiver burden. This research results are congruent with previous studies. A study was conducted to assess the quality of life and burden on family caregivers of children with autism.³⁹ Its results indicated that the caregivers of children with autism reported low quality of life and high burden. Another study suggested that the developmental burden was the strongest predictor of a parent's quality of life, which was an inverse relationship.¹⁵ Moreover, a study on quality of life and burden of family caregivers of children with autism found a negative correlation between FQOL and burden while caring for a child diagnosed with autism.¹²

Considering the relationship between each subscale of FQOL and family caregiver's burden, the results from this

study revealed that there was a negative correlation between family interaction, parenting and emotional well-being and the caregiver burden. It could be implied that the lower family interaction, parenting and emotional well-being, the higher burden of the caregivers, or the higher family interaction, parenting and emotional well-being, the lower burden of the caregivers. The participants in this study were mainly mothers. Due to the nature and characteristics of the behavioral problems and the high need for medical services of children with autism, the mother strives to help her child adapt their life.^{4,5} The woman from South-East Asian culture is often lack of attention and sharing for child rearing from other family members, especially from her husband.⁴⁰ These family interaction problems made family caregivers perceived high burden. In addition, health and education services for children with autism focus only on children and lack of family caregiver involvement in these activities, then caregivers feel awkward in parenting activities at home, at school and in society;^{38,40} the poor children outcomes making them perceived higher burden. Moreover, caregivers of children with autism have less time to relax, pursue their own hobbies or share their feelings with other family members, as well as their friends.²² These problems in family interaction, parenting and emotional well-being made the family caregivers perceive high burden. In fact, there were not many studies that deeply examined the relationships between FQOL and family caregiver's burden, and between their subscales in general and in families of children with autism in particular. However, the results of this study correspond to some previous studies that examined the relationship between family quality of life and family caregiver burden and between their subscales. A study examined FQOL and psychological well-being from a multidimensional perspective in parents of children with autism.²⁶ Its results indicated that caregiver psychological well-being was negatively related to caregiver burden. Moreover, the results indicated that the physical/material well-being and disability-related support were not significantly correlated with burden. In the study, the participants were mostly mothers (80%) and healthy age (36.08 years), therefore, although giving care for autism was relatively strenuous in terms of physical/material well-being, they did not perceive it as a burden. In addition, disability-related support was not yet popular in Vietnam not only for children with autism but also for children with other disabilities, then, the family caregivers assumed the responsibility of giving care and supporting their children by

themselves without social responsibility, they did not perceive it as a burden.^{38,40}

The study provided significant results on the relationships between FQOL and caregiver burden in families of children with autism, there were some limitations that need to be addressed. The relatively small sample size was obtained from one geographical area in Hanoi. The generalizability of the research results is limited to family caregivers of children with autism in other regions of Vietnam. The cultures, traditions, and beliefs between the north and the south of Vietnam may differ somewhat.

Based on research findings, nurses and other health care providers should establish multidisciplinary care teams and provide more family support to families of children with autism to reduce the burden and thereby increase FQOL. Currently, autism-related service providers often spend most of their time on child intervention activities as well as guiding caregivers to intervene for children. The families are not provided enough support to reduce the burden and improve FQOL. For future research, clinical trial studies should be developed to provide interventions that support the family in managing problems faced by the family while living with children with autism in order to reduce the burden of care and increase FQOL, as well as outcomes for children with autism. Moreover, government and non-governmental organizations should offer the benefits that should be provided to these individuals. Policy makers should develop policies to reduce the burden, especially psychosocial and emotional support, and improve the FQOL, then contributing to children outcomes.

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